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General Practice Data for Planning and Research

Summary of a private roundtable

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Introduction

This short paper summarises a roundtable discussion held in summer 2022 about General Practice Data for Planning and Research (GPDPR), a data sharing initiative that the NHS launched in 2021. The roundtable brought together public servants, research organisations, campaign groups, patient groups and private companies with an interest in the project. The roundtable was held under the Chatham House Rule – nothing anyone said is attributed to them or their organisation, unless they have asked for it to be. The discussion does not represent the views of the Institute for Government.

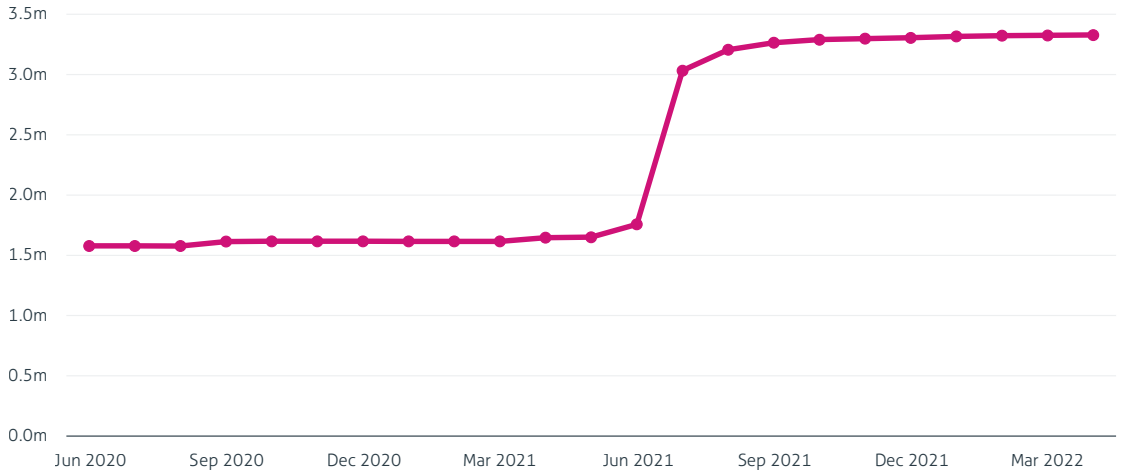
The roundtable forms part of a wider piece of Institute for Government research looking at government data sharing during the pandemic. The project takes six case study areas and uses a roundtable on each to explore what worked well, what could have worked better and what lessons government should learn for the future. Reports on each of the roundtables will be followed by a short synthesis report bringing together common themes.

Overview of GPDPR

In May 2021, NHS Digital announced the launch of a new service to improve the collection of patient data from general practitioners (GPs): General Practice Data for Planning and Research (GPDPR).[1] (It should not be confused with the General Data Protection Regulation, or GDPR, which is legislation about how personal data should be stored, processed and shared.) In the announcement (no longer available on the NHS's website) it noted that the pandemic had led to 'a significant increase in the need for GP data from NHS Digital to support clinicians, researchers, academics and commissioners', which could be used to improve health services through clinical research and operational planning. GPDPR would replace the General Practice Extraction Service (GPES), which 'performed adequately during the pandemic but is based on legacy technology'. The scheme was due to come into being on 1 September 2021.

But the scheme was subject to controversy, with campaign groups and journalists complaining about a lack of transparency and the possibility of the private sector using the data.[2] A legal challenge claimed that 'rushing this major change through with no transparency or debate violates patient trust' and called for a pause to allow patients more time to opt out from their data being included.[3] Several groups referenced a previous scheme intended to bring individual GP records together for research and planning, care.data, which was halted in 2014 and scrapped in 2016 over controversy about a lack of information given to patients (one reason the Major Projects Authority rated the project 'red' – successful delivery appears unachievable).

Figure 1: **Number of patients (England) with a national data opt-out**



Source: Institute for Government analysis of NHS Digital, (MI) National Data Opt-Out, June 2020 to April 2022. Notes: Shows 'number of unique NHS numbers with an associated national data opt-out'. Results shown since June 2020 due to change in methodology. Data last published in April 2022 – dataset now published annually except where the rate changes by more than 0.1% in a month.

Amid the controversy, and with millions of patients exercising their right to opt out of their data being used, the NHS paused the programme in July 2021.[4] It acknowledged that 'we know we need to listen, understand, engage and act on what we learn to get this right, and we are committed to doing so'. Work is ongoing.[5]

One thing you've learnt when engaging with the public around data

As an icebreaker question at the beginning of the roundtable discussion, we asked participants to name the most interesting thing they have learnt when engaging with the public around data. Their answers were as follows:

- People have very informed and nuanced views about the use of data being held about them
- Don't underestimate how strongly the public feel about this
- People are thinking more and more about engagement and how we go about building that into projects from the start
- Interacting with members of the public really helps to put into perspective how the legislation works in practice and what parts of the legislation really matter
- Involving the public can have a significant impact on the outcomes of a project and research
- The patient view and the public view are totally different – you have two very different communities and you need to engage both
- What I've learnt most during the pandemic is how much everything would be easier if we had a National Health record
- You pre-empt or assume the public or patient opinion at your peril
- Officials assumed that because of the pandemic, people's attitudes towards their data being shared had fundamentally shifted and took that for granted
- In addition to patients and the public being two different things, there are many other perspectives in and around this debate
- Using an advisory group was like having a design authority when developing a service and meant privacy was at the heart – there are models for doing this
- How quickly a conversation can change if you are able to explain in a clear way the safeguards that are in place around data (such as the Five Safes*, which is very robust and easily explainable)
- Communication is not sufficient and people are not stupid: they will also take notice and pay attention to technical information, so we shouldn't rely purely on communications

* Five Safes is a framework for using data while protecting it, based on 'safe people, safe projects, safe settings, safe outputs and safe data'. For more information, see Stokes P, 'The "Five Safes" – data privacy at ONS', Office for National Statistics, 2017, retrieved 16 January 2023, https://blog.ons.gov.uk/2017/01/27/the-five-safes-data-privacy-at-ons.

- Fascinated by the complexity that gets thrown up when you carry out these sorts of exercises. Policymakers tend to think that public attitudes can help to cut through the knotty problems but, if anything, you end up with a more complex picture
- The power of metaphors and tools of thought. The metaphors we use when we have these discussions about data really shape some of the outcomes, so we have to be really thoughtful about the way we frame the questions in order to get good discussions that give people a meaningful say.

Key themes from the discussion

- Although much of the discussion focused on what could be improved for similar future schemes, participants identified some successes with GPDPR, including the intentions behind the project being good, promises to improve, conversations being prompted, a general appreciation of the importance of data and the fact that the government paused the scheme following criticism. Patients opting out of their data being used showed public awareness, but could also be a problem if it led to the data becoming unusable.
- The lack of public consent and a lack of communication were real problems, and showed lessons from earlier schemes (particularly care.data) had not been learnt.
- Greater public involvement at all stages of the process, with honest communication from government about risks as well as benefits, and better collaboration between government, the NHS and expert non-government organisations, are vital. This should help improve a project as well as earning public trust.
- There are models that the government and health system can learn from. OpenSAFELY, the field of genomics and a growing body of literature on public engagement, as well as lessons from previous experiences such as care.data, were all cited.

Where GPDPR was successful

The intentions behind the scheme were good and were regarded as such by the public. A report published by the Ada Lovelace Institute shortly after the roundtable discussion found that, despite the concerns of a citizen jury it had convened about how the scheme was to be implemented, the jury recognised the potential benefits of a scheme such as GPDPR.[6]

One participant highlighted that there had been **some real successes in using GP data** during the pandemic: the vaccination rollout was based around using general practice data, including identifying vulnerable people and making special arrangements for them. But this was based on General Practice Extraction Service (GPES) Data for Pandemic Planning and Research, rather than GPDPR.

GPDPR led to the NHS developing **a set of future commitments and promises of future work**, including that GP data would only be analysed inside a trusted research environment (TRE) or equivalent secure computing environment, something several campaigners had long said was essential. But there was disappointment that progress appeared slower than hoped a year on, despite initiatives like the Goldacre Review into 'how the efficient and safe use of health data for research and analysis can benefit patients and the healthcare sector'.[7]

It had also **prompted and accelerated conversations**, enabling different organisations involved in data – including health data – to start having discussions about expectations around safe and trustworthy access to and use of data, and what safeguards should be in place.

There was some **discussion about whether millions of people opting out of their data being used was a success or not**. One participant thought it a "really strong signal" that those who were uncomfortable had exercised their right to opt out, and it had been a catalyst for conversations about the need for opt-outs and better communication (see below). But another said it was something that could have been weaponised politically (other parties could have made it an issue in the press and in campaigning), leading to more opt-outs and destroying the value of the data (research by Wellcome suggests that concerns over the commercial use of the data could take opt-outs to 25%, rather than the current 5%).[8]

The fact that the government paused the scheme was considered a success. Pauses, stops and rethinking show patients and the public that such a scheme will not be bulldozed through, despite the costs of stopping it. Concerns had been raised and something changed, which was "striking" and "significant".

There was **some insight from social care and other health data** (although there were also significant problems with social care data – to be featured in a forthcoming report on the NHS Covid-19 Data Store roundtable, forthcoming). If we all want better use of health data, it has to go beyond general practice data and include the rest of the system as well – secondary care, community care and more. There are challenges around this – investment in data infrastructure (including, for example, data dictionaries, with consistent definitions around the data held) would be needed, and some groups fear a scenario of data held across private companies, local government and central government – but the pandemic showed something could be possible.

The pandemic also led to **a general appreciation of how important data is**. But this needs to move from a theoretical appreciation to a practical one. For example, politicians of all parties make claims about fixing social care and "throw billions of pounds" at doing so, but data does not yet properly inform that conversation. Better data on social care, for instance, would allow a proper assessment of how the system is currently operating and a better understanding of where interventions and investment could be better targeted to improve operations and outcomes.

Consent and communication

What roundtable attendees characterised as **a lack of consent from the public was a problem**. "They could have made a system that was consensual from the start, but they could have done that in 2014 [with care.data] as well." Those setting up schemes like GPDPR might ostensibly prefer opt-out methods (where people have to actively say they do not want to be included) rather than opt-in methods (where people have to sign up). Whichever is used should be consensual, underpinned by informed views and permission, which have benefits for public understanding and trust. NHS England did not write to patients informing them about the scheme, "the only thing that's ever worked" and a key lesson from care.data.

One participant argued that with little notice and little advance information, "it sort of **looks like you're trying to sneak something out** under the cover of a pandemic". One campaign group noted that NHS Digital had removed a 'mythbusting' page around the time a factchecking article was published, coinciding with the programme being reset and webpages changing, suggesting a lack of trust.[9] The communications around GPDPR did not help earn public trust. "It was handled wrong on how it was put to the public. And that's why everybody decided to opt out. They didn't have the right information to make an informed decision on opting out." Citizens' juries suggest that the detail given was not enough. The name of the scheme being so similar to GDPR – the General Data Protection Regulation, the core of the UK's data protection framework – confused people. Ideally, communications would show – not tell people of – the benefits and how the scheme works, rather than just sending out information via press releases. Greater transparency that goes beyond tick-box exercises would also help earn public trust, but it will now be difficult to communicate about GPDPR, as people may be suspicious of the scheme unless shown firm reasons to think otherwise.

There was a great deal of negative publicity. The programme launched with only one voice – NHS England – really advocating for the changes and the importance of data being used in the way intended. That meant a lack of balance in the information that was out there – there was some scaremongering, some headlines that were factually incorrect and some panic ("My data is going to be sold!"). Observers thought the NHS was finding it difficult to respond to stories and rumours, which raised some questions as to how much communications planning had been done.

Announcing that something is going to happen **does not automatically meet the principles of transparency** under the GDPR. Conducting a data processing activity that affects so many people would likely have to involve a variety of methods to satisfy the requirements – "there's not going to be a one-size-fits-all approach that's going to be able to cover every community, every age group, every part of society".

A personal data usage report could help, allowing patients to see audit trails of who was accessing and using their data, when and how. Patients could also see when their records had not been accessed despite promises that they would be. The new NHS data

strategy, *Data Saves Lives*,[10] refers to some real-time usage data, which suggests that this could be technically possible, through NHS login and the NHS app,* and provide a dynamic two-way channel between individual and institution. One analogy given by a participant was mobile banking apps, which allow users to download their bank statements.

Public engagement and collaboration

Participants thought that any programme like GPDPR should go beyond communications into **more developed forms of public engagement from the start**. There are different layers of involvement, from engagement (going out, having conversations, putting on roadshows), to having public advisory boards (and involving the public at every stage), to co-production (with the public coming up with approaches and ways of working). Programmes such as Administrative Data Research UK (ADR UK), which has a public engagement strategy and has also published research on public engagement,[11] and Health Data Research UK (HDR UK), which has a public advisory board, try to involve the public at every stage of the process, with a view to improving their work as well as being transparent. The NHS has since agreed a new approach of 'listening, learning and doing things better', with co-production and engagement built in throughout the process.[12]

Public engagement should **improve the chances of success** for a project: it should avoid ending up with "a bunch of officials convincing themselves they should not be talking to people that they should have been talking to, but saying 'this will be ok, that will be ok, then that step will be ok' until they get to the point where they had to do what they did [pause GPDPR]".

Engagement will generate a spread of views. There is unlikely to be a single consensus, but "this is not a bad thing or a mistake or wrong": different people will feel differently and there is no solution that will suit everyone. Engagement should also be with communities as well as individuals: conversations often neglect collective harms, where entire communities can be discriminated against based on data collected from a few individuals with similar characteristics.

If engagement is only stood up on an ad hoc basis, "there's a lot of capacity building to do before you can have a really meaningful, credible, legitimate discussion about a complicated topic"; having **some standing or existing mechanisms can really help**. These should be able to plug into shallower consultations, deeper collaboration and work with existing partners. Dialogues around data governance that work well tend to have checks and balances built into their designs, and include a range of strategies to hear from people and feed their views through processes that give real legitimacy. Engagement should not be: "We went out, we listened, and we either cherry-picked results or did what we were going to do anyway." This will also require people with community management skills, who can engage with and facilitate conversation

* NHS login allows patients to access a variety of services through websites and apps. The NHS app allows patients to access health services through their tablet or phone. It should not be confused with the separate NHS Covid-19 contact tracing app.

without being defensive when difficult issues arise, and can embrace those who want to join the conversation.

Designing **engagement that is open to scale** is a challenge: there will be many more people who want to be part of the conversation than a small central team can manage, especially if a subject is controversial. If an organisation lacks the ability to scale the conversation, its reflex is to shut it down when it gets too big. Instead, organisations need something designed to provide a template or a toolkit for others to replicate – a model of local dialogue that other places can pick up, so they can have that conversation in their own community.

Involving patient groups from the start, or when the opt-outs started happening, could have helped things go differently for GPDPR. It would have helped people understand how the scheme could benefit health care – including wider benefits to the system, beyond the care of individual patients. Collaboration with GPs could also have been better: they are the custodians of the data in question, but did not seem as supportive of the scheme as might have been expected. They were custodians of the opt-out schemes as well, leading to extra workload on top of the pandemic. Trust in GPs as the first line of defence for many patients could have been leveraged more.

The field of genomics provides a good example of the importance of consent and public involvement even when it is difficult. Data use in the field could lead to worrying prospects – for example, genomic sequencing leading to a DNA database of everyone. According to a roundtable participant, around a decade after collecting genomic data from thousands of people, one genomics initiative realised it had not sought consent for something specific around linking to other medical records. It went and sought consent from everyone again, learning how sophisticated its consent process had to be and giving it an informed and engaged group of people, which informed the rest of its work.

Participants felt **there needs to be better collaboration between government, the NHS and the many organisations in this space**. There are a lot of organisations with expertise on health and data, including health data. The NHS has good intentions in terms of engaging stakeholders, but would do better through collaborating with them, especially organisations with experience of how to engage the public and patients. Several participants regretted the winding down of Understanding Patient Data (an initiative to use research, advocacy and communication to 'put people at the centre of conversations about patient data', which Wellcome announced it could no longer host) and hoped that someone could take over its work who data controllers in government and the health system would listen to due to their political salience. Since the roundtable, NHS Confederation has stepped in to host Understanding Patient Data, so the initiative continues.[13]

Trust

Participants were encouraged that the new NHS data strategy, ***Data Saves Lives,***[14] **starts with public trust** and the need to build confidence.

Onora O'Neill's definition of trustworthiness – Is an individual or organisation competent? Are they reliable? Are they honest? – should be the **pole star for any organisation wanting to be seen as trustworthy**.[15] These answers cannot simply be asserted – they have to be shown, over time. When designing a system, organisations need to consider the evidence they will publish proactively to show their competency, reliability and honesty.

Earning trust requires organisations **to be honest about the risks as well as the benefits** to their activities, and talk about how they will address those risks. The language of 'safe' is better than '100% secure': organisations should be honest that nothing is perfect, but that they are doing their best. Those mitigations should also include sanctions – and showing that those sanctions will be applied – if something goes wrong. Safeguards should be specific for data uses likely to be most toxic with the public, rather than general ones.

Trust can be broken down into different dimensions. One division is between intent and competence: there is a lot of public trust in the intent of the NHS to use data well, but there may be more questions about its technical competence; conversely, the public may trust the intent of big tech companies less but have absolute confidence in their competence to keep data secure. There is a large reservoir of trust in the NHS that it is trying to do the right thing for patients, but controversies like GPDPR could undermine this (while initiatives like OpenSAFELY – see below – and trusted research environments may help). Another dimension is the people involved: the NHS polls highly on trust because doctors and nurses, who have a direct relationship with patients and provide them with care, are trusted. Other officials and bureaucrats may be trusted the same as officials and bureaucrats elsewhere – less than doctors and nurses. There is not a singular trust in the NHS; everyone likes to think of it as one big family, but the least trusted might be doing things that undermine relationships with the most trusted.

Clarity of purpose

Public engagement has worked well where **the purpose of a project has been very clear**. Being clear, simple and open – 'we are doing this thing, this is how long it will last and this is what will happen once we have finished' – is a critical success factor.

A complication is that **the basic data principle of 'collect once, use many times' can go against that** and the general consensus is that it is better to collect and share data when organisations can be really clear about their purpose. There may be some high-level categories – using data for direct care, population health management, planning and research – which could be useful.

Time horizons

Participants suggested that the simplest thing to have made GPDPR better would have been **not to have announced it until basic details were already in place**, such as who would have access to the data, what rules there would be in relation to access, how the process would be governed and by whom, and how the data would be secured. Announcing the programme as if it were already happening, without having done all of the necessary thinking, left large unanswered questions that the media and others picked up on, questions that took some time to respond to, and allowed sometimes inaccurate information to fill the vacuum. There is also an argument that the NHS has had a long time to get a scheme like GPDPR right, based on the care.data experience, with that scheme being halted in 2014 and scrapped in 2016.

It takes time for people to get comfortable and have a good dialogue. Pressure to get something done quickly can be counterproductive, and a pandemic context, of everything having to be done rapidly, is not a normal operating context. But speeding through a process should not mean avoiding the conversations that need to be had.

Approaches to work

Having a **multidisciplinary team** helps. If organisations have data protection experts in the room from the beginning, they can consider risks in the right order and build in data protection by design. An earlier awareness of both patient concerns and data protection concerns might have led to different technical solutions being built in much sooner. Some participants felt that many problems are design problems masquerading as legal, policy, security or technical issues – you need designers from the start who can think about end-to-end processes and the outcomes that the service is trying to achieve.

Following that, **iteration has to be built into the process**. The chances of getting everything right straight out of the gate are low; there needs to be a learning process. On data, nobody has a 20-year advantage of being able to look back and see what the correct path to plot was. Sometimes unintended consequences require a change of direction to achieve what was intended, which could be the outcome of the postponement of the scheme.

Showing what is possible and learning from elsewhere

Participants highlighted several examples that future data sharing initiatives could learn some lessons from, even if they do not cover all the challenges the NHS might face in its own schemes.

One was the **OpenSAFELY** project, which allows access to around 98% of electronic health records in England. It was built from the start in a way that was designed to develop trust and be 'provably trustworthy' – the data remains in situ, with a trusted research environment or software platform allowing researchers to take analytics

to the data and get results back, rather than bringing the data to the analysts.[*16] All analysts have to be approved and fully document how they go above and beyond data protection law. Patient and public involvement is important – with conversations, citizens' juries, and a group of 'digital critical friends' who are essentially a public advisory group recruited from an open process, which aims for broad representation (in terms of ethnicity, gender, age and level of digital literacy) and meets every two weeks for two hours to go through things on the platform in detail. The 'friends' are not just told what OpenSAFELY is doing, but are also asked about how they think things should work, what is going right and what is going wrong. They are embedded into the project approvals process, and asked in retrospect whether the projects agreed were in fact the right projects to approve. If the answer is ever 'no', they use a process known as learning governance, which Understanding Patient Data espouses, to learn from the experience. The platform was limited to Covid-19 data as Control of Patient Information (COPI) notices underpin it.

Clinical trials have also shown what is possible, with lots of work on public acceptability and how to communicate in the most appropriate way with patients. But these have all been aligned around a global threat – Covid-19 – and rely on people signing up and informed consent, rather than access to GP records with an opt-out or dissent model of consent.

But there has been **a lack of learning from previous initiatives**, particularly care.data. In June 2022, the House of Commons Science and Technology Committee asked the then health minister, Lord Kamall, why things had unfolded as they did despite knowing the importance of trust and engagement, he was unable to answer the question (though he had only been in post for a short time).[17]

Other

There is often an undue focus on privacy at the expense of other concerns, with privacy conflated with other issues around purpose, ethics and transparency. Conversations about data often become synonymous with privacy, which is important, complicated, nuanced and defined by the context of particular uses, but there are other ethical concerns around access to data and the value of data. For example, there may be privacy concerns about companies being able to see an individual's data, but there are others beyond that, such as selling the data on and profiting from it (purpose).

There should be **consequences if something goes wrong**. There should be a single-strike policy if someone breaks a contract with NHS Digital – they should not get any more data. Otherwise, you cannot reassure patients about how their data is being used.

Some participants had concerns that **the current changes to the structure of the NHS**, with NHSX and NHS Digital becoming part of NHS England's Transformation Directorate,

* Citizens' juries found OpenSAFELY to be the most trusted data initiative during the pandemic – see NIHR Applied Research Greater Manchester, 'Citizens' juries on health data sharing in a pandemic', NIHR Applied Research Greater Manchester, (no date) retrieved 16 January 2023, https://arc-gm.nihr.ac.uk/projects/Citizens-Juries-on-Health-Data-Sharing-in-a-Pandemic.

could create some uncertainty about who would take what role and who would be responsible for any version of GPDPR in the future.

Key lessons and recommendations from participants

Participants drew out several key lessons and recommendations for government based on the GPDPR experience. These included the following:

- The public should be involved at various different stages of the process, including in the co-production of project aims at the start, where appropriate.
- The NHS should do more in collaboration with patient groups and the many civil society organisations and campaigners who have expertise around health and health data – NHS England's new approach has already taken these lessons on board.
- Government and the NHS should consider the recommendations of the Goldacre Review, particularly recommendations 1 to 6 on platforms and security (including using trusted research environments and acknowledging shortcomings in pseudonymisation and trust in protecting privacy) and recommendations 22 to 25 on governance (including understanding and improving approvals processes for access to data and having a 'frank' conversation with the public about commercial use).[18] The NHS's *Data Saves Lives* strategy says it supports the Goldacre Review's recommendations and is taking them forward.[19]
- Making sure experts from multiple disciplines – including data protection – are in the room from the start of designing a project like GPDPR is crucial, which NHS England has told us is happening.
- Transparency needs to go beyond 'tick-box' exercises to earn public confidence – showing, rather than telling, how a data sharing project works and what the benefits are would help (NHS England's new approach again reflects this).
- Good communication is necessary, though not sufficient. Communication needs to happen at different levels – there needs to be basic information for everyone and more detailed information that experts can scrutinise.
- There should also be detailed information for patients on how their data is being and has been used. This could include a personal data usage report so they can see who has accessed their medical records and for what purpose.
- There needs to be information and clarity about redress – what happens if there are any data breaches or other issues. This means that redress mechanisms and sanctions need to be in place from the start.

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